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EVALUATING SERVICES FOR PATIENTS WITH CHRONIC ANOREXIA NERVOSA

by

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor
of Clinical Psychology

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May 2003

CONTENTS

	Page
1. Chapter One: Treating individuals with chronic anorexia nervosa: An opportunity for research and innovative practice	1
1.1 Treatments for anorexia nervosa	5
1.2 Issues in working with individuals with chronic anorexia nervosa	7
1.3 Specialist treatments for chronic anorexia nervosa	9
1.4 Community treatments for chronic anorexia nervosa?	13
1.5 Recommendations for future research and treatment	15
1.6 References	16
2. Chapter Two: An examination of factors predicting long-term duration of illness in anorexia nervosa	28
2.1 Introduction	28
2.2 Method	31
2.3 Results	32
2.4 Discussion	35
2.5 References	36
3. Chapter Three: Treatment experiences of patients with chronic anorexia nervosa: a thematic analysis	42
3.1 Introduction	42
3.2 Method	45
3.3 Results	48
3.4 Discussion	59
3.5 References	64
4. Chapter Four: Qualitative research: the right to remain sceptical	69
4.1 Planning and design	69
4.2 Data collection	70
4.3 Data analysis	74
4.4 Writing up	75
4.5 Conclusion	77
4.6 References	78
Appendices	
Patient Information Sheet & Consent Form	A1.1 - 1.2
Ethics Committee Approval	A2.1 - 2.2
Instructions for authors	A3.1 - 3.3

LIST OF TABLES

2.1	Evidence for specific indicators of poor outcome in anorexia nervosa	30
2.2	Means of three numerical factors and age	33
2.3	Chi-square analyses for frequency of presence of individual prognostic variables	34
3.1	Salient themes divided by research questions	50
3.2	Summary of themes by research questions	60

ACKNOWLEDGEMENTS

I would like to say thank you very much to my clinical supervisors, Dr Wendy Phillips and Dr Tony Winston for helping me turn the ideas for this research into a practical project, and for being ready with advice and suggestions when it seemed things were not going to plan. I would also like to thank all the staff at Woodleigh Beeches for being so friendly and encouraging throughout the duration of the study, and for being prepared to present the research project to their patients. My sincere appreciation goes out to the patients who agreed to be interviewed for this study, for their honest and open reflections on their experiences and for freely giving their time to talk to me. I would like to express my thanks to Dr Caroline Meyer, my academic supervisor, who even when ill was available for support and reviews, and to Dr Stephen Joseph, research tutor who helpfully reviewed early drafts of my work. Also a word of thanks to Hayley Poole for inter-rater reliability checks, which were much appreciated. Finally I'd like to say a huge thanks to my long suffering other half, Stephen, who has had to accept over the last few months that his girlfriend is someone who emerges from the study only to eat and sleep!

DECLARATION

This research was carried out under the supervision of Dr Wendy Phillips and Dr Tony Winston, who helped me in the design of the study, and provided access to participants, and Dr Caroline Meyer, who provided research experience and support. I carried out the clinical note review, and conducted, transcribed, and analysed all the interviews. Apart from the collaborations noted above, this thesis is all my own work. Authorship of any papers that result from this work will be shared with the above. The thesis has not been submitted for a degree to any other

university. The literature review is being prepared for submission to Clinical Psychology Review (Sullivan, Meyer, Philips & Winston, in preparation), the brief paper is being prepared for submission to the European Eating Disorders Review (Sullivan, Phillips, Winston & Meyer, in preparation), and the main paper is being prepared for submission to the International Journal of Eating Disorders (Sullivan, Winston, Meyer & Phillips, in preparation). See Appendices 3.1 – 3.3 for instructions for authors.

WORD COUNT (excluding tables)

Literature review	5795
Brief paper	2273
Main paper	5802
Reflective paper	2681
TOTAL	16551

SUMMARY

Around 20% of patients who develop anorexia nervosa will have an illness that takes a chronic course, and has not resolved after 10 years or more. Treatment approaches for these individuals tends to be overlooked in the research literature, which has focused on attempts to identify who is likely to develop chronic anorexia nervosa, rather than how to most appropriately work with those who do. This paper suggests that currently used treatment approaches should be evaluated, and the results of such evaluations used to guide the design and implementation of new interventions, tailored to the substantial needs of this patient group. The first study examined the utility of five hypothesised prognostic factors in differentiating patients with a medium and long-term course of anorexia nervosa, and found that high age of onset, and long duration of illness before treatment appeared to differentiate the two groups. These factors may facilitate identification of these patients at initial presentation, such that tailored treatments could be implemented at this point. In the second study, patients with chronic anorexia nervosa were interviewed to explore their experiences of helpful and unhelpful treatment, and their recommendations for treatment. A thematic analysis was conducted on the transcribed interviews. Identified themes suggested that helpful aspects of treatment were characterised by collaborative, and normalising approaches, supportive contact with other patients, and experienced and understanding clinicians. Unhelpful treatments were characterised by frightening inpatient admissions, abnormal treatment, competitive contact with other patients, and inexperienced or disinterested clinicians. The implications of these results for future research and treatment in this area are discussed.

Chapter One

TREATING INDIVIDUALS WITH CHRONIC ANOREXIA NERVOSA: AN OPPORTUNITY FOR RESEARCH AND INNOVATIVE PRACTICE

ABSTRACT. *Chronic anorexia nervosa, with a duration of 10 years or more, is a serious disorder that receives limited attention in the research literature. Published studies address outcome and prognosis, but fail to investigate current practice, new treatments, or the patient's experience of their difficulties. This paper describes the course and prevalence of chronic anorexia nervosa and issues for clinician and patient engaging in treatment. Specialist treatment options and alternative, community-based, treatments for individuals with other chronic difficulties are discussed, and potential areas for research and innovative practice are highlighted. These patients may not be best served by specialist eating disorder services, and innovative community approaches may be more appropriate. Problems in conducting research with this patient group should not result in the substantial needs of these individuals being overlooked in the design of new treatments, and the author calls for more evidence based practice in this area, particularly treatment evaluation and implementation of novel approaches to helping patients with chronic anorexia nervosa.*

Anorexia nervosa is described in DSM-IV (APA 1994) as the refusal to maintain a minimally normal weight for age and height (<85% of that expected), intense fear of gaining weight or becoming fat even though underweight, disturbance of body image, and amenorrhea in post-menarchal females (absence of at least 3

consecutive cycles). There is no official definition for chronicity in anorexia nervosa, and it can appear arbitrary to stipulate a particular threshold at which the disorder could be definitively said to become chronic. Definitions in the literature include a duration of disorder of 10 years or more (Noordenbos, Jacobs & Hertzberger, 1998), presence of strong anorexic symptomatology for over 5 years (Levenkron, 2000), and onset before 25 years of age with continuation of disorder after 25 years of age (Mynors-Wallis, Treasure & Chee, 1992). For the purposes of this review, I will consider chronic anorexia nervosa to be a disorder lasting 10 years or more without significant remission.

Outcome studies have tried to ascertain the prevalence of chronic anorexia nervosa, but unfortunately the conclusions of many such studies are compromised by methodological concerns. These include negatively biased samples recruited from specialist services, inconsistent definitions of good, intermediate, and poor outcome, varying duration of follow up, and different study populations (adolescents and adults). Consequently, the studies have produced heterogeneous results, with limited power to generalise.

Reviewing the available studies, the majority suggest that around 20 to 25% of individuals with anorexia nervosa will have a poor or chronic outcome, retaining most or all of the symptoms of anorexia nervosa over an extended follow up period, (Beumont, 2001, Fichter & Quadflieg, 1999, Löwe, Zipfel, Buccholz, Dupont, Reas & Herzog, 2001, Richards, Baldwin, Frost, Clark-Sly, Berrett & Hardman, 2000, Steinhausen, 2002, Strober, Freeman & Morrell, 1997, Tanaka, Kiriike, Nagata, & Riku, 2001). A smaller number found rates of 25 –50%

(Eckert, Halmi, Marchi, Grove & Crosby, 1995, Gillberg, Rastam & Gillberg, 1994, Palmer & Treasure, 1999, Ratnasuriya, Eisler, Szmulker & Russell, 1991) and one study reported that over 60% of their sample had a poor outcome (Rosenvinge & Moulund, 1990).

Although particular groups are more at risk for developing anorexia nervosa, and thus have a higher incidence of the disorder, such as females in late adolescence and early adulthood where incidence may be as high as 0.5% to 1% DSM-IV (APA, 1994), in the general population anorexia nervosa is a rare disorder. Based on presentation to mental health services, general population incidence is estimated at about 5 cases per 100,000 of the population per year (Hoek, 1995). Applying this incidence to the last UK census (ONS, 2001) which stated that the UK population was nearly 59,000,000, then each year it would suggest there would be approximately 2950 new cases of anorexia nervosa in the UK. If, at a conservative estimate based on the outcome studies, 20 % of these have a disorder that takes a chronic course, we might expect there to be 590 new chronic anorexics each year. Clearly this is not a large number, but these individuals may be consuming large amounts of treatment and clinician time (Palmer, Gatward, Black & Park, 2000).

Although recovery is still possible after a prolonged duration of anorexia nervosa (Noordenbos et al., 1998), the likelihood of recovering significantly decreases when an individual's disorder becomes chronic (Löwe et al., 2001, Ratnasuriya et al., 1991). In addition, the form of anorexia nervosa may vary over a long term course, with some patients developing bulimic symptoms such as bingeing and

purging (Eddy, Keel, Dorer, Delinsky, Franko & Herzog, 2002, Strober, Freeman & Morrell, 1997) which can further reduce the likelihood of recovery (Fichter & Quadflieg 1999, Herzog, Schellberg & Deter, 1997, Richards et al., 2000, van der Ham, van Strien & van Engeland, 1998), and complicate treatment approaches. With the likelihood of recovery decreasing year by year, the numbers of such patients can easily build up in stretched specialist services, utilising scarce resources, and potentially preventing the treatment of other non-chronic patients.

Medical complications, that can occur throughout the course of anorexia nervosa, such as osteoporosis, dental erosion, cardiovascular complications, reproductive problems, brain structural changes and endocrine complications (Leonard & Mehler, 2001, Treasure & Szmulker, 1995), are often more common, and more severe in patients with a chronic course of the disorder, with up to 67% experiencing serious medical comorbidity at a 12 year follow up (Herzog et al., 1997). These issues can compromise the individual's quality of life, and may result in premature death. Cardiovascular complications account for around half of the reported deaths from anorexia nervosa, and other causes include sequelae of emaciation, suicide, and alcohol abuse (Neumärker, 1997). Crude mortality rates can be up to 17 times higher in individuals with chronic anorexia nervosa than would be expected in an age-matched population (Fichter & Quadflieg, 1999, Norring & Sohlberg, 1993), and an observed aggregate mortality rate of 0.56% per year based on a review of 42 published studies (Sullivan, 1995) suggests the mortality rate is twice as high as that of other female psychiatric inpatients, who one might consider a comparable patient population.

1.1 TREATMENTS FOR ANOREXIA NERVOSA

Effective treatments for anorexia nervosa are of interest to those concerned with the needs of the chronic patient, as they offer the potential to find some aspect of treatment that will promote early recovery, and therefore reduce the numbers of patients who develop chronic anorexia nervosa. Available interventions for anorexia nervosa can be separated into medical management and therapy, although the two are usually combined to maximise efficacy. Medical management focuses on physical aspects of the disorder, such as weight restoration, and monitoring physical state, and may be conducted in inpatient or outpatient settings, depending on the needs of the patient and the severity of their illness. Inpatient admissions can be lengthy (McKenzie & Joyce, 1992, Palmer et al., 2000) and costly (Striegel-Moore, Leslie, Petrill, Garvin & Rosenheck, 2000) and patients may not maintain the weight gains they achieve in hospital unless they are adequately supported with psychotherapy, during admission and following discharge.

Randomised controlled trials have been conducted on a range of different psychotherapy approaches. Family therapy with adolescents is effective in promoting engagement, and maintaining weight gain (Crisp, Norton, Gowers, Halek, Levett, Yeldham, Bowyer & Bhat, 1991, Gowers, Norton, Halek & Crisp, 1994), and progress is made even when the patient and parents are treated separately (Le Grange, Eisler, Dare & Russell, 1992, Eisler, Dare, Hodes, Russell, Dodge & Le Grange, 2000). This, combined with inpatient treatment, seems to be the treatment of choice for adolescents with anorexia nervosa. Such

approaches appear less effective in adult patients with both brief (Hall & Crisp, 1987) and longer term family therapy (Dare, Eisler, Russell, Treasure & Dodge, 2001) proving slightly better than non-specific approaches, but with small weight gains in the study groups.

Other psychotherapy trials with adults with anorexia nervosa have evaluated a range of psychotherapies, such as cognitive behavioural therapy, (Channon, DeSilva, Hemsley & Perkins, 1989), supportive therapy (Russell, Szmukler, Dare & Eisler, 1987), psychodynamic therapy (Hall & Crisp, 1987), cognitive analytic therapy (Treasure, Todd, Brolly, Tiller, Nehmed & Denman, 1995), and psychoanalytic therapy (Dare et al., 2001). All are more effective than medical management alone, and generally produce significant improvement in one third to one half of patients. Unfortunately, considerable numbers of patients do not respond to these approaches.

As outcome studies have suggested that a long duration of illness before receiving treatment leads to poor outcome (Howard, Evans, Quintero-Howard, Bowers, & Andersen, 1999, Norring & Sohlberg, 1993, Ratnasuriya, Eisler, Szmukler & Russell, 1991), and treatment trials suggest a better outcome for adolescent patients, there has been some investigation into whether early intervention might improve the prognosis for patients with anorexia nervosa. A review (Schoemaker, 1997) found no evidence that early intervention did positively affect outcome, and a recent outcome study (Ben-Tovim, Walker, Gilchrist, Freeman, Kalucy & Esterman, 2001) noted that treatment was not related to outcome for patients with anorexia nervosa. This suggests that

attempts so far to prevent individuals developing chronic anorexia nervosa need further attention. However, if the development of chronic anorexia nervosa cannot be prevented, research is needed to identify effective ways to work with this patient group.

1.2 ISSUES IN WORKING WITH INDIVIDUALS WITH CHRONIC ANOREXIA NERVOSA

Individuals with chronic anorexia nervosa present challenges above and beyond those of working with anorexic patients more generally, and often have a complicated treatment history, including repeated unsuccessful attempts at many interventions (Noordenbos, Oldenhove, Muschter & Terpstra, 2002). As a result they may express minimal interest in treatment and recovery (Geller, Williams & Srikanth, 2001). Unlike many other medical and psychiatric patients with chronic difficulties, they may be extremely resistant to change, and may sometimes refuse treatment. Some individuals with chronic anorexia nervosa begin to see themselves as incurable, which can prevent them asking for, or accepting, help (Noordenbos et al., 2002) while for some, chronic anorexia nervosa can become a way of life (Palmer, 2000) and the thought of trying to alter this will be extremely frightening.

However, there are some grounds for optimism. In a recent review of individuals with chronic eating disorders (Noordenbos et al., 2002), 73% expressed a wish to try a new treatment for their eating problem, although based on their past experiences of treatment, only 23% believed they could improve. Chronic does not mean incurable, and even after many years of illness patients can benefit

from further input. However, the difficulties in engaging individuals with chronic anorexia nervosa, suggest that research into issues of engagement may be of benefit.

It can be extremely challenging for clinicians to work with chronic anorexic patients because they understand that the individual may die from their illness, but need to concentrate on establishing an engagement with the patient to enable them to work together, and try not to force treatment upon them, or attempt to shock the patient into recovery with frightening facts about the likely outcome of their disorder (Geller et al., 2001). Because clinician and patient may have different aims in treatment, this can lead to battles over treatment goals, and the patient may drop out of treatment. These experiences can reduce the likelihood of the patient seeking treatment in the future.

Yager (1995) recommends monitoring for ‘undue therapeutic zeal’ where clinicians assume that a patient’s lack of recovery is solely attributable to the standard of previous treatment, and thus believe that things will be different with their intervention. This can lead to frustration for both parties, and potentially clinician burn out. However, at the other extreme, it is imperative not to blame the client. Relapse in other chronic conditions, such as schizophrenia, is often accepted by clinicians as being beyond the patient’s control, whereas relapse or lack of progress in chronic anorexia nervosa may be seen as within the patient’s control or deliberate, and may therefore be responded to with anger and frustration by clinicians (Beumont & Russell, 1993). Anecdotally it seems that working with these patients takes a heavy toll on clinicians, and it would be

interesting to evaluate their thoughts and feelings about these patients, and the potential impact these may have on the therapeutic relationship, and the patient's likelihood of making significant changes.

1.3 SPECIALIST TREATMENTS FOR CHRONIC ANOREXIA NERVOSA

A review of Medline, Psycinfo, Cinahl, Embase, and the Cochrane library found no published research studies on specific treatments for chronic anorexia nervosa. This lack of research evidence is perhaps understandable as this group is small in number, notably hard to engage and offer treatment to, has a treatment history that would exclude them from most new studies, and tends to be spread across a large range of services. Researchers may therefore feel there are insufficient numbers to merit investigation, or generate useful conclusions. In addition, treatment evaluation within this group is likely to be hard because it may be a challenge to agree on criteria for success, which may involve only very small changes for the individual. Because of the lack of evidence, this section will describe and review treatments advocated by experienced specialist clinicians in the field of eating disorders, as well as approaches from other areas that may be useful for this population.

A number of clinicians advocate taking a more accepting, less recovery-focused approach with individuals with chronic anorexia nervosa to avoid once again recycling them through previously unhelpful treatment regimes, and to reduce the pressure placed upon them (Goldner, 1989, Kaplan, 2002, Palmer, 2000, Yager, 1995). If patients feel they cannot benefit from further recovery-focused treatment, they can instead be offered outpatient medical management for

monitoring and support. This can vary in intensity from weekly input from a specialist team (Strober, 1997) to review appointments every few months (Palmer, 2000). It is important that this is not seen as having written the patient off as beyond help, and it requires considerable skill to achieve a balance between not applying pressure whilst still communicating hope. If this balance is achieved then the continuity, support and warmth of this relationship may be the biggest strength of this approach, reducing the individual's sense of isolation (Kaplan, 2002, Palmer, 2000) and potentially providing a space over an extended period of time for the individual to consider whether they can address their difficulties. It would be informative if services who work with patients with chronic anorexia in this way could evaluate service consumption by these individuals, as well as outcomes for the patient engaged in a supportive management approach. This would help to confirm or refute the anecdotal evidence that these patients utilise large amounts of services' time without any discernible benefits.

A low intensity treatment option for individuals with chronic anorexia nervosa is support groups (van Furth, Noordenbos, Jacobs & van Elk, 1999). Although not offering active treatment, support groups can help patients feel more accepted and decrease feelings of social isolation. For some patients, the long term supportive contact allows them to consider re-engaging with active treatment for their eating problems. This is an interesting and fairly low cost approach to service provision for chronic anorexic patients because it permits more relaxed and informal monitoring, whilst providing a supportive environment for the patient, without the pressure to change their behaviour. It also maintains contact

with specialist services such that patients can access further, more active treatment if they wish. Services may be wary of setting up groups for individuals with chronic anorexia nervosa for fear that the contact with others may incite competition, or have a negative effect (Maher, 1980), but it seems that once patients have settled in to the group, the supportive elements outweigh the initial competitive concerns (van Furth et al., 1999). Such groups offer the opportunity to potentially evaluate quality of life for individuals with chronic anorexia nervosa who are not in active treatment for their difficulties, and to really begin to understand the impact on the individual of the physical, psychological, and social problems associated with chronic anorexia nervosa.

Motivational interviewing approaches (Miller & Rollnick, 1991) are effective in assessing and treating clients with a short duration of anorexia nervosa (Treasure & Schmidt, 2001, Treasure & Ward, 1997) and may be useful in working with clients with chronic anorexia nervosa (Kaplan, 2002). Geller et al. (2001) have adapted this approach for individuals with chronic anorexia nervosa. They describe a ‘clinician stance’ that increases the likelihood of client engagement, by explicitly communicating that responsibility for change is down to the client. The main clinician behaviours that comprise this stance are; communicating beliefs that foster client self-acceptance, not making assumptions about the client or their behaviour, and working collaboratively to understand the functions of their disorder (Geller et al., 2001). Although there is, as yet, no published outcome data for this intervention, it does appear to be a promising approach, particularly as it seems likely to reduce clinician burn out and client drop out,

and allow the patient to decide what changes they feel able to make, and how they might achieve this.

In extreme cases of chronic anorexia nervosa, compulsory hospital admission may be indicated. This is a sensitive issue and the literature suggests imposed treatment should only be considered as a last resort when life and health are seriously endangered and when a patient demonstrates incapacity to understand the implications of their disorder (Dresser, 1984, Goldner, 1989). The decision to enforce admission is ethically, and therapeutically complex. For some patients it adversely affects the therapeutic relationship, while others may find reassurance in the fact that clinicians are prepared to take control over something they cannot themselves control.

The issue is further complicated by evidence that cognitive impairments in extremely low weight anorexia nervosa can impair the individual's ability to make use of therapy, or potentially make informed decisions about their need for treatment (Kingston, Szmukler, Andrewes, Tress & Desmond, 1996). Evidence has also shown that adolescents who remain at an extremely low weight without treatment, may suffer irreversible brain damage (Lambe, Katzman, Mikulis, Kennedy, & Zipursky, 1997), hence clinicians need to weigh up the costs and benefits of enforcing treatment, but proceed with caution (Dresser, 1984).

In severe, intractable anorexia nervosa, leukotomy has been used in conjunction with intensive psychotherapy to allow therapeutic engagement and acceptance of weight gain in patients who would otherwise be unable to manage this (Morgan

& Crisp, 2000). Long term follow up suggested the procedure had benefited the patients, and was justifiable as a last resort treatment for patients with exceptionally severe anorexia nervosa. Because working with these clients can engender feelings of hopelessness in clinicians, some other extreme solutions to their difficulties have been suggested such as palliative care (O'Neill, Crowther, & Sampson, 1994) and euthanasia (Vandereycken, 1998), although these suggestions have, perhaps understandably, been questioned by others (Palmer & Treasure, 1999, Ramsay & Treasure, 1996, Williams, Pieri & Sims, 1998).

1.4 COMMUNITY TREATMENTS FOR CHRONIC ANOREXIA NERVOSA?

In addition to treatment at specialist eating disorder services, there are community treatment approaches designed for patients with other chronic and enduring psychiatric problems, which may have some utility in the treatment of individuals with chronic anorexia nervosa. Reintegration of the individual back into the community is a key element in any successful treatment for individuals with chronic anorexia nervosa (Smye & Geller, 1997). Many specialist eating disorder services are some distance away from the individual's home, which can increase the pressure on them and exacerbate their social isolation. Beumont (2001), in making recommendations for managing long term anorexia nervosa, suggests that treatment should be shifted from centres of excellence to a 'periphery of excellence' that utilises primary care, day hospital and community resources. Day services, which involve patients in management and decision making, as well as conducting many of their activities in non-clinical community settings, can be effective in reducing isolation, and facilitating community

integration for clients with severe mental health problems (Foulds, Wood & Bhui, 1998). Future research should investigate whether these services might benefit individuals with chronic anorexia nervosa.

Chronic anorexia nervosa can create a similar pattern of social disability to that experienced by individuals with chronic schizophrenia (Beumont, 2001) and as such may benefit from approaches designed for other chronic disorders.

Assertive community treatment, and intensive case management, where a trained mental health professional is responsible for direct care of the individual and for co-ordinating the input they need to manage outside hospital, are approaches that have reduced hospital admissions and decreased costs of care for chronically ill patients in the US, whilst improving patient care (Burns & Santos, 1995, Marshall & Lockwood, 1998, Quinlivan, Hough, Crowell, Beach, Hofstetter & Kenworthy, 1995, Solomon, 1992). In the UK this has been shown to promote engagement with services, although without the same decrease in hospital admission that makes the approach so cost-effective in the US (Burns, Creed, Fahy, Thompson, Tyrer & White, 1999, Tyrer, Morgan, Van Horn, Jayakody, Evans, Brummell, White, Baldwin, Harrison-Read & Johnson, 1995). The concept of case management, and intensive input to help someone with limited chance of recovery to optimise their opportunities, lead a more normal life, and have access to active treatment as necessary may be an approach that could benefit individuals with chronic anorexia nervosa, especially if it increases engagement. A problem with the adoption of this approach may be persuading community teams to accept patients with chronic anorexia nervosa on to their caseloads in order to evaluate the utility of this intervention, as community

clinicians may be unwilling to take on patients who seem so complex without considerable training and support, and may feel that these patients are best treated by specialist services. This area merits further investigation, perhaps exploring the views of patients with chronic anorexia nervosa about community treatment, as well as an assessment of how viable this treatment option would be. It would also be beneficial to identify the levels of specialist support required by community teams to work with these patients, and ideally conduct initial pilot studies of the approach with a small number of patients.

1.5 RECOMMENDATIONS FOR FUTURE RESEARCH AND TREATMENT

Anorexia nervosa becomes a seriously debilitating chronic condition in over 20% of individuals who develop the disorder, characterised by social isolation, medical comorbidity and a significantly increased risk of mortality. In spite of the serious nature of this illness, research on effective ways of working with these individuals has been neglected and clinical decisions about interventions are likely to be based on personal experience rather than available evidence. Currently available treatments may be hopelessly inadequate, or they may be everything these individuals need, but without evaluation we really have no idea.

Although there are problems in conducting research with this group, notably low numbers, resistance to treatment, and problems defining and evaluating ‘good’ outcome, I believe these concerns can be overcome with innovative thinking, careful consideration of methods and the application of qualitative approaches to

explore the experiences of patients and clinicians. Suggested areas for future research that could usefully inform treatment provision for this group include;

- Issues of engagement with treatment for individuals with chronic anorexia nervosa
- Staff experiences of working with this group
- Service consumption and outcome of these individuals within current treatment frameworks
- Continued exploration of the possibilities offered by motivational approaches to treatment
- Evaluation of quality of life for individuals with chronic anorexia nervosa
- Potential efficacy of community-based treatment approaches

Attention to the above areas will help us to accurately identify the needs of individuals with chronic anorexia nervosa. In time this could provide the necessary evidence to facilitate the design and implementation of new, evidence-based treatment approaches that maximise the potential benefits for patients with this chronic disorder.

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Chapter Two

An examination of factors predicting long-term duration of illness in anorexia nervosa

This study examines whether five factors, compiled from information routinely collected at initial eating disorders assessment, have any utility as predictors of a long-term duration of anorexia nervosa. Two patient groups are compared; the first with a medium-term duration of illness (5-9 years), and the second with a long-term duration of illness (10 years or more). Retrospective analysis of clinical notes was conducted to gather information on the following five factors; age of onset of illness, duration of illness before treatment, BMI at assessment, purging behaviours, and psychiatric comorbidity, and the two groups were compared on individual factors. Significantly more patients in the long-term group had a high age of onset and a prolonged duration of illness before treatment. Findings suggest that these factors may be useful in predicting longer-term course, and their utility should be further investigated.

2.1 INTRODUCTION

A considerable proportion (21%) of patients with anorexia nervosa develop a chronic course (Steinhausen, 2002), defined as a disorder lasting 10 years or more ((Noordenbos, Jacobs & Hertzberger, 1998). These patients are difficult to treat (Geller, Williams & Srikaneswaran, 2001, Goldner, Birmingham & Smye, 1997), and may consume large amounts of specialist treatment (Eckert, Halmi, Marchi, Grove & Crosby, 1995, Palmer, Gatward, Black & Park, 2000), with no

evidence of treatment positively affecting outcome in this group (Ben-Tovim et al., 2001, Norring & Sohlberg, 1993, van der Ham, van Strien, & van Engeland, 1998). Consequently, outcome research has tried to detect patient variables that might predict a long-term course so that these patients can be identified, and offered appropriate treatments. Focusing on information available at initial assessment; age of onset of illness, duration of illness before treatment, BMI at assessment, purging behaviours, and psychiatric comorbidity, their predictive value thus far is mixed, as shown in Table 2.1 overleaf.

Table 2.1 – Evidence for specific indicators of poor outcome in anorexia nervosa

Factor	Predictive of poor outcome	Not predictive of poor outcome
High age of onset	<ul style="list-style-type: none"> • Ratnasuriya, Eisler, Sz mukler & Russell (1991) • Richards et al. (2000) • Tanaka, Kiriike, Nagata, & Riku (2001) 	<ul style="list-style-type: none"> • Ben-Tovim et al (2001) • Strober, Freeman & Morrell, (1997)
Pre-pubertal age of onset	<ul style="list-style-type: none"> • Bryant-Waugh, Knibbs, Fossom, Kaminski & Lask (1988) • Walford & McCune (1991) 	<ul style="list-style-type: none"> • Strober, Freeman & Morrell, (1997)
Long time to treatment	<ul style="list-style-type: none"> • Herzog et al. (1999) • Howard, Evans, Quintero-Howard, Bowers, & Andersen (1999) • Norring & Sohlberg (1993) • Ratnasuriya et al. (1991) • Rosenvinge & Mouland (1990), 	<ul style="list-style-type: none"> • Ben-Tovim et al (2001), • Herzog, Schellberg & Deter (1997)
Low BMI at presentation	<ul style="list-style-type: none"> • Hebebrand et al. (1997) • Howard et al (1999) • Herzog et al (1999) • Tanaka et al. (2001), 	<ul style="list-style-type: none"> • Ben-Tovim et al (2001), • Herzog, et al. (1997)
Purging behaviours	<ul style="list-style-type: none"> • Fichter & Quadflieg (1999) • Herzog et al. (1997) • Richards et al. (2000), 	
Psychiatric comorbidity	<ul style="list-style-type: none"> • Ratnasuriya et al. (1991) • Rosenvinge & Mouland (1990), 	<ul style="list-style-type: none"> • Herpertz-Dahlmann, Wewetzer & Remschmidt (1995) • Herzog et al. (1999)

Because the evidence was inconsistent, and many of the studies had notable methodological difficulties (negative sample bias, differing definitions of outcome and small group sizes), it seemed worthwhile to further investigate these factors. This study uses a straightforward methodology to compare presence of the above factors at initial assessment in two different groups of patients, one with a medium-term (5-9 years), and the other with a chronic, or long-term (10 or more years) duration of illness. If the factors do indeed have validity as predictors of long-term course, it was hypothesised that:

- 1) The long-term group would have significantly higher age of onset, longer time to treatment, and lower BMI at assessment than the medium-term group.
- 2) More patients in the long-term group would have individual factors present at their initial assessment.

2.2 METHOD

The clinical notes of patients with a medium-term (5-9 years) and a long-term (10 or more years) history of anorexia nervosa, who were in contact with the eating disorders service over a one-year period, were reviewed to gather demographic details and information on the five factors. Factors were scored as present based on the following criteria:

Age at onset - This was scored as present if the patient had developed anorexia nervosa after the age of 20 (Tanaka et al., 2001) or before the age of 12 (Bryant-Waugh et al., 1988).

Time to treatment – This was scored as present if the patient had been ill for over 3 years before initially receiving treatment (Rosenvinge & Mouland, 1990).

Low BMI – This was scored as present if the patient had a BMI of 13 or less at initial assessment (Hebebrand et al., 1997, Tanaka et al., 2001).

Purging behaviours – There is no available evidence regarding the relationship between intensity of purging behaviours and outcome (Bulik, Sullivan, Fear & Pickering, 2000), hence for this study, this factor was scored as present if purging behaviours were recorded at the initial assessment.

Psychiatric comorbidity – This was scored as present if details of another psychiatric illness were recorded at initial assessment.

The gathered data were analysed using SPSS.

2.3 RESULTS

Table 2.2 overleaf shows the descriptive characteristics of the two groups, medium-term (n=21) and long-term (n=16). There was one male in the medium-term group (4.76%) and two males in the long-term group (12.5%), which is consistent with previous research (Rastam, Gillberg & Garton, 1989, Palmer, 2000). Independent samples t-tests were conducted on the variables, age of onset, time to treatment and BMI. Only one patient in the sample (long-term) had an age of onset <12 and exploratory analysis showed that her inclusion in the t-test calculation did not significantly skew the results.

Table 2.2 – Means of three numerical factors and age

	Medium-term (n=21)	Long-term (n=16)
Age (a)	24.38 (sd 6.77)	34.75 (sd 7.67)
Age of onset	17.48 (sd 6.81)	19.94 (sd 5.93)
Time to treatment (b)	3.29 (sd 2.24)	9.43 (sd 6.75)
BMI at assessment	17.01 (sd 2.34)	16.01 (sd 2.63)

(a) difference significant at $p<.001$ level

(b) Due to heterogeneity of variance, data were transformed using a natural log transformation. Following transformation the difference was significant at $p<.005$ level.

There were no significant differences between the two groups on BMI, or age of onset, although the long-term group do have a mean age of onset close to the proposed cut-off (>20) for poor outcome. The difference in time to treatment was significant. There was also a significant difference in age between the two groups.

Chi-square analyses were conducted to compare the two groups on presence of the five hypothesised prognostic factors; age of onset of disorder (<12 or >20), time to treatment (>3 years), low BMI at assessment (≤ 13), presence of purging behaviours, and psychiatric comorbidity, as shown in the table overleaf.

Table 2.3 – Chi-square analyses for frequency of presence of individual prognostic variables

Prognostic factor	Group	Absent	Present	Chi-square significance
1. age of onset	Medium	19	2	.009
	Long	8	8	
2. time to treatment	Medium	14	7	.030
	Long*	4	10	
3. low BMI	Medium	20	1	.206
	Long	13	3	
4. purging behaviours	Medium	14	7	.104
	Long	15	1	
5. psychiatric comorbidity	Medium	8	13	.137
	Long	2	14	

**data for first treatment at specialist eating disorder service unavailable for 2 patients*

Significantly more patients in the long-term group had the factors, age of onset, and time to treatment, present at initial assessment. There were no significant differences in presence of low BMI, and purging behaviours, although the data does suggest that more patients in the medium-term group had purging behaviours at initial assessment. Psychiatric comorbidity showed no differences, but the small group sizes, and high recorded frequency may reduce the power of this factor.

Summary of results according to hypotheses

1) The long-term group would have significantly higher age of onset, longer time to treatment, and lower BMI at assessment than the medium-term group.

The only variable that significantly differentiated the medium and long-term groups was time to treatment.

2) More patients in the long-term group would have individual factors present at their initial assessment.

There was a significantly higher presence of the factors, age of onset, and time to treatment in the long-term group, but no difference on BMI, purging behaviours, or psychiatric comorbidity.

2.4 DISCUSSION

The study produced a mixed set of results, and while it cannot be stated that all five factors examined here have predictive utility, there is some limited evidence for specific factors. High age of onset is recorded significantly more often at initial assessment in patients in the long-term group, consistent with a number of previous studies (Ratnasuriya et al., 1991, Richards et al., 2000, Tanaka et al., 2001). Duration of time before specialist eating disorder treatment seems to merit further investigation, although the skewed distribution of the two groups studied here prevent any definite conclusions about its prognostic value. Low BMI, or purging behaviours, did not occur more frequently in the long-term group, rather the trend (although not significant) appeared to suggest that purging behaviours at assessment were higher in the medium-term group, which contradicts the available evidence (Fichter & Quadflieg, 1999, Herzog et al., 1997, Richards et al., 2000). Recorded comorbid psychiatric problems were high in these two groups, and did not differ significantly. However, this may be the least accurate factor, because when assessing, it can be hard to distinguish whether these are separate illnesses, or part of the anorexic presentation (Pollice, Kaye, Greeno & Weltzin, 1997).

This was a preliminary investigation into whether easy to identify factors, collected as part of initial assessments, can help to distinguish patients whose disorder may take a long-term course. Although it was constrained by small sample size, arbitrary allocation of patients to the two different groups, and the potential for patients in the medium-term group to move into the long-term group over time, the results suggest that clinicians should consider the possibility that a patient's illness might continue long-term, if at assessment they state that their illness began after the age of 20, and they have waited over 3 years before seeking treatment. At present there is no evidence to suggest that giving more treatment to these patients is effective (Norrington & Sohlberg, 1993), and we cannot conclude that because a longer duration of disorder before treatment suggests a long-term course, earlier treatment will necessarily guarantee an earlier recovery (Schoemaker, 1997). However, if we can potentially identify patients at initial assessment, who might be more likely to have a long-term course of anorexia nervosa, it provides the opportunity to specifically direct treatment efforts towards them, and ideally to research new approaches that might prevent their illness continuing long-term. The devastating psychological, physical, and social consequences of long-term anorexia nervosa, should make helping these individuals a treatment and research priority.

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Chapter Three

Treatment experiences of patients with chronic anorexia nervosa: a thematic analysis

Objective: The focus of this article is to identify elements of treatment that are perceived as helpful and unhelpful by patients with chronic anorexia nervosa, and to consider their treatment suggestions for this disorder. **Methods:**

Interviews focusing on experiences of treatment were conducted with 11 patients with chronic anorexia nervosa. Thematic analysis was used to code the interviews. Broader themes were split according to the main research questions.

Results: Helpful treatments were characterised by collaborative, and normalising approaches, supportive contact with other patients, and experienced and understanding clinicians. Unhelpful treatments were characterised by frightening inpatient admissions, abnormal treatment, competitive contact with other patients, and inexperienced or disinterested clinicians. Treatment approaches suggested by patients are also described. **Discussion:** Patients with chronic anorexia nervosa are notably difficult to successfully treat. Their views, experiences, and suggestions about helpful treatments should be incorporated into the design of new treatments, and future research.

3.1 INTRODUCTION

According to a recent review of outcome studies (Steinhausen, 2002), nearly 21% of patients with anorexia nervosa do not recover and their illness takes a chronic course, continuing for over ten years without significant remission

(Noordenbos, Jacobs & Hertzberger, 1998). The likelihood of recovery, and patients' willingness to seek treatment appears to decrease significantly as the disorder becomes chronic (Löwe et al., 2001). Chronic anorexia nervosa has serious medical consequences, including osteoporosis, cardiovascular complications, and brain structural changes (Leonard & Mehler, 2001, Treasure & Szmulker, 1995) and the highest rate of mortality of all functional psychiatric disorders (Sullivan, 1995). The combination of physical, psychological and social problems associated with this disorder can have a devastating impact on quality of life for the individual with chronic anorexia nervosa.

Outpatient medical monitoring with or without supportive therapy is the standard treatment approach for chronic anorexia nervosa (Palmer, 2000, Strober, 1997, Yager, 1995). However, it has been suggested that motivational approaches (Geller, Williams & Srikanth, 2001), where the clinician hands responsibility for change to the client, may be useful in establishing a therapeutic alliance and decreasing resistance to treatment (Kaplan, 2002). Low intensity community support or self help groups (van Furth, Noordenbos, Jacobs & van Elk, 1999) may also be a cost effective way of maintaining contact with these patients. These approaches have not been evaluated, and clinicians need to use their own experience, clinical intuition, and the structure of the service in which they work, to guide their decisions about how to work with these patients.

Treatment research in chronic anorexia nervosa has focused on prognosis and outcome, which has provided consistent data on the numbers of patients likely to develop chronic anorexia nervosa, but largely inconsistent evidence on

prognostic indicators of poor or chronic outcome (*See Pike (1998) for a comprehensive review*), and no studies of treatment efficacy have been conducted with this group. There are many explanations for this lack of treatment research in chronic anorexia nervosa; small numbers of patients (.001% of population developing chronic course in a year, Hoek, 1995, Steinhausen, 2002), resistance to treatment (Goldner, Birmingham & Smye, 1997, Macdonald, 2002), complicated and ultimately unsuccessful treatment histories (Noordenbos, Oldenhav, Muschter & Terpstra, 2002), and problems establishing useful outcome criteria for evaluation (Jarman & Walsh, 1999). The 'gold standard' for outcome research, complete recovery, may be unobtainable in this group so intervention goals need to be modest, individual, and collaboratively agreed between patient and clinician (Geller et al., 2001), which is likely to minimise generalisability.

However, there are approaches that could facilitate treatment research in this area. Qualitative methodology has been used effectively to evaluate couple and family therapy for a number of years (Bischoff & McBride, 1996, Bowman & Fine, 2000, Sells, Smith & Moon, 1996), and has been recommended for evaluating existing and novel treatments within psychiatry (Crawford, Weaver, Rutter, Sensky & Tyrer, 2002). In recent years, a number of investigators have successfully used qualitative approaches to investigate specific aspects of anorexia nervosa. Deconstructive approaches to discourse have been used to illuminate patients' views of themselves as anorexic, and identify issues that may hamper therapeutic engagement, (Surgenor, Plumridge & Horn, 2002).

Information on the experiences of living with anorexia nervosa long term was

gathered through qualitative analysis of letters and questionnaires (Noordenbos et al., 1998, Noordenbos et al., 2002) and repertory grids (Button & Warren, 2001). Aspects of recovery have been explored in narrative analyses of patients' recovery stories (Garrett 1997) and a grounded theory investigation of parental attributes that facilitate recovery from anorexia nervosa (Sharkey-Orgero, 1999).

If qualitative methods are effective in evaluating treatments, and representing the experience of anorexia nervosa, it seems likely that they may be a useful tool in investigating the treatment experiences of patients with chronic anorexia nervosa. This study uses thematic analysis (Boyatzis, 1998) of interviews with patients with chronic anorexia to answer the following questions; what aspects of treatment have been helpful? What aspects of treatment have been unhelpful? What treatments would the patient recommend if they had the choice? The results of this study will suggest treatment components to maximise engagement and reduce resistance, and inform the design of future treatment approaches.

3.2 METHOD

The study was conducted at a secondary referral eating disorders service in the UK. In order to maximise the number of potential participants, a more inclusive definition of chronic anorexia nervosa was used. Seventeen patients with a history of anorexia nervosa of 5 years or more who were receiving treatment at the service were identified from case notes, and invited to take part in the study. To ensure a representative range of responses, 11 patients who met the criteria

but had dropped out of contact with the service within the last 12 months, were also invited to participate.

Current patients were given an information sheet and consent form (see Appendix 1), and a verbal explanation of the study by their keyworker at a routine appointment. Discharged patients were sent a letter explaining the study and inviting them to participate. It was made explicit to all patients that the interviewer was independent of the clinical team, personally identifiable information would not be communicated back to the clinical team, and their decision about participation in the study would in no way affect their current or future treatment with the eating disorders service.

Nine of 17 (52.9%) current patients and 2 of 11 (18.2%) discharged patients agreed to participate in the study. Of these, 10 were female and 1 was male. The average age of the participants was 30.5 years, and the average duration of their illness was 10.2 years. This suggests that patients in the study did have long histories of anorexia nervosa. Seven of the 11 patients (63.6%) had received either general psychiatric or specialist eating disorders treatment prior to their current treatment episode, and 7 of the 11 (63.6%) had 1 or more inpatient admissions.

Interviews were conducted in patients' homes so that their responses were not influenced by a treatment setting. The focus was on current and past experiences of treatment, both with the eating disorders service, and with other treatment providers. Patients were also asked what treatments they would offer if they were

asked to provide a service for patients with chronic anorexia nervosa. Interviews lasted from 45 to 80 minutes, and were audiotaped for later transcription and analysis.

It has been suggested that qualitative research findings are more readily interpretable by the reader, and potential areas of bias are more explicit, if the researcher's perspective is stated (Elliott, Fischer & Rennie, 1999). Hence, I will briefly explain my reasons for conducting this research, and my expectations of likely outcome. After working in eating disorders as a researcher and a trainee clinical psychologist, I developed a sense that the needs of chronic anorexic patients were not being met, which inspired the current study. I feel my main potential area of bias was that I anticipated mostly negative treatment appraisals from study participants and I was surprised when this was not the case. Interview data were coded inductively to control for this potential negative bias and to ensure that I did not misinterpret or misrepresent the sentiments of the interviewees.

Thematic analysis as described by Boyatzis (1998) was used to analyse the data as it provides a clear and easy to follow methodology for analysis, facilitates inter-rater reliability checks, and allows descriptive presentation of qualitative research findings (Berg, 2001). Initial coding was data-driven and inductive, in order to accurately identify the themes present in the data, rather than impose an external framework upon them. Upon identification of the main themes, the research questions were applied to each theme. When the contents of the theme addressed more than one research question, it was split into subcategories. Hence

the only ‘theory-driven’ element of the analysis was the splitting of themes according to the original research questions.

The data analysis process is described below:

Step One: All interview transcripts were inductively coded on a line-by-line basis to ensure maximal representation of the data in subsequent themes. Salient items were noted as coding proceeded.

Step Two: Transcripts were recoded, and related items collated to form small ‘pre-themes’

Step Three: Pre-themes were recoded into 6 larger, more inclusive themes that captured the salient issues in the transcripts. If a theme appeared to contain information that related to more than one research question, the theme was split into subcategories.

Step Four: A coding explanation was written, describing the 6 themes and their subdivisions.

Step Five: Three research interviews were randomly selected, and coded by an independent rater to test reliability

Step Six: Inter-rater reliability was calculated (*initial agreement was 71% which rose to 75% after the ‘inpatient’ code description was rewritten*).

3.3 RESULTS

The results of the thematic analysis generated 6 salient themes directly relating to treatment experiences and suggestions. Because of space limitations, themes that represented the views of less than 5 interviewees were not included in this analysis. The first 3 themes were divided according to the research questions, as

described below, because they contained information that was relevant to all three questions

Question 1. What aspects of treatment were helpful?

Items within themes were coded as ‘treatment helpful’ (H) if they described a patient’s direct experience of treatment that they considered advantageous or beneficial.

Question 2. What aspects of treatment were unhelpful?

Items within themes were coded as ‘unhelpful treatments’ (U) if they described a patient’s experience as negative, unpleasant, or of no benefit.

Question 3. What treatments would you offer if you were providing a service?

Items within themes were coded as ‘treatment suggestions’ (S) if they were responses to questions about setting up a service, or spontaneously generated ideas that patients mentioned they would like as treatments, or would recommend. Focus was restricted to abstract discussion of what might be beneficial rather than a description of previously experienced treatment.

The remaining 3 themes were smaller, and each related to only one research question. Table 3.1 illustrates the 6 themes and shows how they were split according to the research questions.

Table 3.1 – Salient themes divided by research questions

	<i>Number</i>
Theme 1 – Clinician attributes	
(H) Positive clinician attributes	10
(U) Negative clinician attributes	8
(S) Recommended clinician attributes	10
Theme 2 – Normalisation	
(H) Normal treatment helpful	7
(U) Abnormal treatment unhelpful	5
(S) Normality retained within treatment	6
Theme 3 – Contact with other patients	
(H) Positive experience of contact	5
(U) Negative experience of contact	5
(S) Recommendations for contact	5
Theme 4 – Collaboration and flexibility (H)	7
Theme 5 – Inpatient experiences (U)	7
Theme 6 – Less structure (S)	7

The results are presented descriptively in order to ground the presentation in the data, and to fully illustrate the range of views of the interviewees. Quantitative information was used only to indicate the number of interviewees who mentioned a particular theme as illustrated in the above table. In subsequent presentation of the themes, individual patients will be identified by a number, to enable the reader to clearly see which participants gave a particular response. For reasons of space, it has not been possible to present a response for every interviewee who endorsed a theme. Instead, responses have been selected that appear to convey the essence of each theme, whilst describing any interesting nuances within the theme. Efforts have been made to ensure all interviewees' experiences are adequately represented, although individual differences in experience (having more treatment, inpatient admissions, or entirely positive, or negative experiences) affect the number and range of themes an individual discusses. A minority of excerpts have had to be abridged, and this is indicated in the text by (.). Care was taken to retain the intended meaning of the statement when it had to be abridged.

Theme 1 – Clinician attributes

This theme describes attributes of individual clinicians and teams that were perceived by the patient as helpful, or unhelpful, as well as recommendations for how this relationship ideally could be.

(H) Positive clinician attributes

Helpful clinicians have knowledge and experience, and are able to understand what the patient is going through:

(1) when you speak to her she did make everything seem ok, and she questioned you in a way that you needed

(6) I find with X that she really seems to understand how I feel, and to work with that rather than just giving me general advice

(3) she knows what's going on in your head

It is also important that they are able to offer support and security for the patient:

(9) the staff on the ward are more supportive about, you know, the time when you're eating

(5) I suppose just the sense of having the time and security and the people around you and this kind of environment has helped me come out of myself

(10) very supportive, that's all I've ever had really here its been very supportive

(U) Negative clinician attributes

Unhelpful or negative experiences with clinicians were principally characterised by a lack of understanding of the patient's difficulties:

(9) my weight had gone up (.) I just burst into tears and this member of staff's reaction was oh for god's sake that's what you're here for isn't it, to put weight on

(1) if you've got no idea what a person is going through and you haven't read that much about it then there's a limited amount of help you can give a person

A lack of interest in the individual was also considered detrimental:

(8) it always seemed as if they were talking about cases they already knew (.) they weren't basically talking to me

(4) I mean they just deal with you as though you're a case and not a person, they think you don't know anything

While the behaviour of some clinicians can appear punitive:

(10) she used to shout at me when I had lost weight, and she'd be like, what are you playing at? And it was very upsetting

(S) Recommended clinician attributes

The main recommended attributes for clinicians were support and the ability to listen:

(8) the more treatments where they do actually listen to people and they do understand, that would be very useful

(1) the first thing they need is someone who says no we really don't think you're a selfish cow, we don't think that at all, and 100% full on support

Patients also felt clinicians should have knowledge and understanding of eating disorders:

(11) you want someone to say really you're not alone, you have got an eating disorder, and this is what its like, and this is what happens

(5) I think it would be more beneficial to have the staff actually there specifically looking at working with the eating disorder patients and having the, you know, the experience I suppose, or the qualifications

Theme 2 - Normalisation

This theme captures the view that effective treatment was normalising, less helpful treatment made patients feel abnormal, and that while the need for treatment was acknowledged, ideally they felt this should help them feel, and behave, as normally as possible.

(H) Normal treatment helpful

Interviewees stated that it was beneficial for them to be treated as a normal person and to be exposed to situations encountered by normal people:

(6) but they've always made it feel, you know, not the way I eat is normal, but I am normal and that, you know, lots of other people experience the same sort of problems, which I find helpful

(7) in a way you got to do normal things that we didn't do, like gardening or (.) painting, as I say, what normal people do

(10) just to try and get a bit more normality, and try and like, get into the pattern of what I'd be doing if I was at home

(U) Abnormal treatment unhelpful

This describes the perception that the treatment, staff behaviour, or food amounts are abnormal, and have no real world relevance:

(1) and they're going this is what a normal person eats and I looked at them and was like no I'm not stupid you know, just anorexic

(4) they'd like watch you after you eat, watching all the time, its horrible. I mean how are you supposed to act normally if you're being treated abnormally?

(5) I think what's the point of bringing me in here and going through all this when I need to be doing it out there

(S) 'Normality' retained within treatment

These suggestions acknowledge that the individual has an illness and needs treatment, but that a sense of normality and contact with the real world is still valuable:

(8) a difficult part of treatment is that, whether you take the decision to take someone out of their environment, and whether that therefore makes a treatment into something that's too divorced from whatever they're going to try stepping back into

(5) I think contact with everything that goes on out there is actually important to maintain, and for you to be seeing what is actually normal (.) hard to get the balance of reiterating that actually, you know, you're ill and you're in hospital because you need to be in hospital

However, they also advocate treatment taking a graded approach towards achievement of normal behaviours, with a particular focus on eating:

(5) but I do actually think it would be good to start moving off the table, not necessarily all at once, and then you sit with the other (non-anorexic) clients

(1) give you 6 small meals a day and they increase the size of them gradually which is what you need because you can't just suddenly start eating a load of food

Theme 3 - Contact with other patients

This theme describes the challenge of deciding whether or not it is beneficial to have contact with other anorexic patients.

(H) Positive contact with other patients

Contact with other anorexics offers an opportunity for identification, and provides reassurance that patients are not alone:

(7) I know it sounds terrible but it was quite nice to know that there were people who were worse off than you, you know, if you thought you were bad then there was like, people who were much worse

(11) when I started meeting other people at (.) then I realised I wasn't on my own and then you start sharing experiences, that's what helped

Other patients can also provide support and encouragement:

(1) we kind of were all cheeky together because we knew that we didn't want to be there

(10) we strive to help each other, encourage each other to eat (.) its really good

(U) Negative contact with other patients

Exposure to other patients can have a negative effect due to comparison and competition, and social contagion of anorexic behaviours:

(5) its quite easy to get dragged down if, you know, oh everything is anorexia, anorexia, food, food, food and all you hear is, you know, going on about it

(8) what I found a bit demoralising was that they (other patients) were constantly trying to find ways around the rules and all the rest of it and I was frightened that the longer I was in there, that might rub off on me

(9) Those initial times just being with anorexic people, it was almost like I became aware of calories, and aware of things about food that I hadn't been, it was almost like I learned things there that really I wish I had never understood

(S) Recommendations for contact with patients

Contact with other anorexics was advocated because it could offer the individual understanding and encouragement. This may be perceived as particularly important if a patient has had the experience of not receiving these things from staff:

- (2) contact with maybe other anorexics might help (.) you might work together as a team to encourage each other to share experiences
- (3) it might even help if you had willing people that had eating disorders could manage to go in and speak to some of them (.) and say to them look I know what you're going through
- (4) maybe to talk to other people who've got sort of problems, they might understand

The three themes that follow are not split, because they address only one question.

Theme 4 – Collaboration and flexibility (H)

This theme describes the helpful aspect of being collaboratively involved in treatment:

- (6) We'll sort of reach the decisions together so that's quite good cos I sort of feel more involved in it all rather than just being told what to do, which I find really helpful
- (10) you sort of feel in here that its, you're working towards your own care, you take part of the responsibility, even though its not a significant amount

It is also advantageous if the treatment regime has the flexibility to allow patients the time they need to make changes:

- (9) I think it gave me space and I use my time there to try to turn it around each time, I'm still fighting
- (11) they're very good, you go at your own pace

(2) I feel like I'm going to progress, erm I've been on a plateau with my weight for about four weeks now (.) and I feel happy with that and I feel now I'm ready to move on again

Theme 5 – Inpatient experiences (U)

Although helpful aspects of inpatient treatment have been mentioned in other themes, this theme describes a range of unhelpful experiences that patients had as inpatients. Excessive focus on weight gain and food was hard to cope with:

(5) they just made sure you put on some weight and then I got out as quick as I could, there were a couple of admissions like that

(10) that was an absolute nightmare because I was just refed (.) I was on bed-rest for 7 months and then after that, I was discharged (.) I never had any therapy or body image work or anything

The inpatient experience could feel punitive and frightening:

(4) there was one thing that I definitely wouldn't eat, even I didn't like and they said oh you're lying, I mean they made me eat it, I've never ever liked that, never ever and I had to eat it and I felt so sick after

(9) because my weight was so low I was admitted straight away (.) on to full portions straight away. I was (.) absolutely terrified

(3) they'd threaten me if I left they'd section me, but of course then I didn't realise what it meant and it frightened me, that word section, I didn't know what it meant, whether they could keep me forever

Theme 6 – Less structure and more flexibility (S)

Interviewees suggested that more flexible, less structured approaches would be helpful, ranging from reducing the food focus during admission to having flexible drop-in services that patients can access as necessary:

(3) I don't think there should be such a strict regime on when dinner time is like bang on 12 o'clock cos because I think a lot of them worry (.) they think oh my god its coming up to 12 o'clock, we've got to eat in a minute. I think it should be a bit more, not relaxed because they're not going to be relaxed, but I don't think it should be dead on a certain time, and then the meals come wandering in

(8) inpatients (.) they're always weighed at the same time of day, and the same routine and they get to write out a list of food and something, but I think it would actually be, personally I think it would be better for them if they had no sort of hand in it really

(4) I don't think that it should be too structured, I mean you should go to this place and feel relaxed. I think they should have like dieticians available for you to see, doctors, and lots of information and books and things, and they should give you plans on how you can help yourself

(11) I'd have, definitely a walk-in, a drop in centre where you don't have to be referred by your GP (.) they can just knock the door and just say I want to come in, I want to speak to somebody

3.4 DISCUSSION

This study was intended as a step towards filling the gap in the research literature on treatment evaluation for patients with chronic anorexia nervosa. The study used a qualitative methodology to enquire about the experiences of this patient

group. Table 3.2 summarises the findings with regard to the three stated research questions.

Table3.2 - Summary of themes by research questions

What aspects of treatment were helpful? Positive clinician attributes Normalising treatment Collaboration and flexibility Positive contact with other patients	Specific components <i>understanding, experience, support</i> <i>treated ‘normally’, exposed to normal situations</i> <i>collaborative and flexible treatment approach</i> <i>identification, reassurance, support, encouragement</i>
What aspects of treatment were unhelpful? Negative clinician attributes Abnormal treatment Inpatient experiences Negative contact with other patients	 <i>lack of understanding, lack of interest, punitive</i> <i>treatment abnormal, no real world relevance</i> <i>excessive food & weight focus, frightening, punitive</i> <i>competition, behaviour contagion</i>
What treatments would you offer if you were providing a service? Recommended clinician attributes Normality retained within treatment Less structure Contact with patients	 <i>support, listening, understanding & knowledge of eating disorders</i> <i>real world exposure, gradual learning of more normal behaviours</i> <i>reduce food focus, more informal outpatient services</i> <i>understanding and encouragement</i>

The findings suggest that services are already providing a range of approaches that patients have found helpful, but that these could be tailored to better serve their needs. A review of these experiences and recommendations suggests the following four areas that merit consideration.

Clinicians

Clinicians working with chronic anorexic patients need to be experienced, understanding and supportive, and perhaps more importantly, they need to convey these attributes to the patient to facilitate engagement, and build up trust. Patients with chronic anorexia can be challenging, and potentially frustrating to work with because of their apparent resistance to change (Geller et al., 2001), and clinicians working with these patients need adequate support and supervision to ensure they do not direct their frustrations at the patient. Displaying frustration can be experienced as punitive and frightening, and is likely to compromise therapeutic engagement, and thus limit the potential for change.

Flexibility and normalisation in treatment

Inpatient treatments should gradually give the patient more responsibility to increase the likelihood that they will cope with the demands of life when they leave the inpatient setting. Specific suggestions include reducing the strict, food and weight focused structure, involving patients in decisions about their treatment, and allowing them to do activities that are more relevant to the real world. Patients acknowledged that this would be difficult to achieve because of the challenge in finding a balance between their need for specialist treatment with its boundaries and containment, and their need to maintain contact with

normal life and have some flexibility. Approaches such as assertive community treatment (Marshall & Lockwood, 1998) and collaborative day care (Foulds, Wood & Bhui, 1998) that work with patients with enduring difficulties in their community of origin, may merit consideration as a way to offer patients with chronic anorexia nervosa the support they need, but within the ‘normal world’.

Informal outpatient treatment

Provision for patients with eating disorders, however limited should be available in every town, ideally something quite informal, where they can drop in and receive information, or chat, or see a clinician if they wish. Services such as this have been offered to patients with enduring mental health difficulties (Holloway, Murray, Squire & Carson, 1996) as part of an intensive case management approach and were shown to be helpful, and appreciated by the patients. Eating disorders services may need to consider whether they could offer similar open access services, or if they could liase with community treatment providers to provide this type of facility for their patients.

Contact with anorexics

Positive contact with other anorexics is beneficial and should be offered as part of treatment, but negative, competitive contact is unhelpful, and can cause patients to leave treatment early as a way of avoiding interaction with patients they feel may be dragging them down. At inpatient level, it may therefore be worthwhile for clinicians to pay more attention to the inter-group dynamics, not to remove the problems, as it is important for patients to learn to handle these difficult interactions, but to understand what is happening so that they are able to

help individual patients manage their issues with other patients. At outpatient level, a potential way of reconciling these two positions may be to offer support groups for patients with chronic anorexia nervosa, as suggested by van Furth et al. (1999), where attendance is optional, thus allowing patients to access support should they require it, but to take time out if they feel the contact is detrimental.

In considering these recommendations, we need to hold in mind that the current study has its limitations. The patient sample was small and may not generalise to other patients with chronic anorexia nervosa, in spite of the considerable agreement and repetition of themes across the 11 interviews. There is also the possibility that the patients who volunteered their experiences for this research may have been a biased sample, by the very nature of their decision to participate. They were not biased in a negative direction, as I had presumed upon commencing the research, rather the majority were quite positive. In this study, no attempt was made to verify patients' reports, because it was considered more important to capture the patients' experience. Objectively, their experience may differ from that of a clinician working with them, but in this situation what is true and false is actually less important than how the patient experiences the situation, and the effect that has on their ability to engage with, and make optimal use of, available treatment.

In spite of the above limitations, this study successfully utilised the experiences of patients with chronic anorexia nervosa to gain insight into helpful and unhelpful aspects of treatment, and what treatments patients would choose to offer. It has generated a number of recommendations for treatment adaptations,

and novel treatments, that may potentially be useful to clinicians considering new directions for treatment within their services. Further research needs to evaluate current, and new treatments in this area so that in future we can adapt the way we work with these patients to better meet their needs.

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Chapter Four

Qualitative research: the right to remain sceptical

In this paper, I will reflect on my experience of the process of conducting qualitative research. I have chosen to restrict my reflections to the qualitative research process in order to allow ample space for consideration of the issues involved. The paper will describe the process of my qualitative research from initial thoughts through to completion.

4.1 PLANNING AND DESIGN

I began with considerable doubts about qualitative research. I was sceptical about whether it could produce the results I needed, whilst being unclear whether one was permitted to demand a particular results profile from the approach. I had the worry that I believe afflicts many inexperienced qualitative researchers, that at the end of the process I would have a huge, unintelligible mass of data that I could never hope to understand and utilise. I also wondered whether I would have the necessary commitment to see it through, as I often find that I am inspired by the ideas and data collection side of research, but that I have become disinterested by the analysis and writing up stage, and the immersion in the data demanded by a qualitative approach, seemed likely to dampen the enthusiasm of the most dedicated researcher. However, I accepted these concerns as challenges rather than obstacles, and began the qualitative research process.

Selecting which qualitative method to use was difficult because there is such a range of available approaches, and the descriptive literature has a seemingly

infinite capacity to confuse. I knew that I needed a predominantly non-interpretive approach, as the study was preliminary, and actually giving a voice to this group of patients was an essential part of the study, and I eventually decided on thematic analysis. I was aware my study population would preclude exact replication of the thematic analysis procedures advocated because it could not be subdivided (Boyatzis, 1998), but I felt reasonably confident there was sufficient flexibility in the approach to adapt to the needs of my study.

Because I was studying the treatment experiences of patients with long-term difficulties, I worried that patients who wished to vent their negative experiences and who would perhaps have nothing positive to say may be overly represented amongst my participants. Clearly this would still be an accurate representation of their experiences but it would restrict the study's capacity to identify helpful treatments. I was also apprehensive about submitting an ethics application to conduct a qualitative research project, and I think I worried that the committee would be more likely to find fault with the qualitative methodology. With hindsight, it seems I may have been projecting my doubts about the approach on to them, as they did not question the use of qualitative methodology, and seemed keen for the needs of these patients to be investigated.

4.2 DATA COLLECTION

I remember feeling ill-prepared when arriving at someone's house for an interview armed only with a small list of areas for discussion and a dictaphone. I think this was because the last research study on which I worked involving interviews in people's homes, required the completion of a lever arch file full of

structured interviews and questionnaires. Within the interviews I found myself struggling to maintain a qualitative interviewer stance. In my previous role, as a more quantitative researcher, interviews were a process of amassing facts that needed to be true. However, as a trainee clinical psychologist, interviews tend to be assessments, or preludes to a therapeutic engagement, where information is gathered, but the focus is on developing an understanding of the individual's difficulties. As a qualitative researcher, the interview tries to gain an understanding of the patient's experience, in whatever way they wish to convey that. The difficulty in having these different role experiences was maintaining a qualitative approach, in that if a patient discussed problems they were having I had to stop myself switching into trainee mode and trying to offer therapy, but similarly, if it seemed clear that what a patient was telling me was untrue, for example stating that their weight was much higher than it obviously was, I had to try not to move into quantitative researcher mode and seek out the truth. Holding back these other approaches in order to allow the interviewee to communicate their experiences required considerable vigilance during the interviews.

A related issue was that prior to the interviews, I had not really considered the potentially negative impact on the interviewee even though discussion of past experiences clearly has the potential to cause emotional distress (McLeod, 1994). It was only as the interviews progressed that I realised the distress they could cause, particularly when one participant felt she did not wish to receive feedback because she thought it would be too distressing. I had also failed to consider the impact the interviews might have on me. In retrospect, it seems obvious that if you are discussing intimate details of someone's life and they feel comfortable

talking to you, they may talk about other, more difficult issues. Having not considered this as a possibility, I had not arranged any clinical supervision sessions when designing the study, and I had to think about how to manage this. Based on this experience I feel it is important for anyone who is planning to conduct qualitative research involving in-depth interviews, to arrange clinical supervision from the start, because even if no difficult issues arise from the interviews, the opportunity for a debrief is invaluable.

Having accepted that the interview could have an impact on both the interviewee and myself, I began to reflect on how this might influence the data it produced. The interviewer's behaviour will affect the interviewee's responses which will in turn affect the interviewer's behaviour (Finlay, 2002) and this intersubjective cycle continues throughout the interview. Hence interviewing changes the meaning and understanding of experience (Beer, 1997) and can potentially alter the phenomenon that is being investigated (Finlay, 2002). As a result, it cannot be assumed that data gathered by one interviewer, would be the same if a different interviewer had conducted the interview (Polkinghorne, 1991). This raised questions in my mind about the validity of the data that are gathered from the interview process.

An interesting thing I noticed whilst conducting the interviews was that my original fears about interviewees being entirely negative about their treatment experiences were unfounded. During discussions with staff about approaching their patients to ask them to participate in the study, a number of them commented that they thought a particular patient would consent because 'they

were in that kind of place.’ On questioning the meaning of this, I discovered they meant that the patient perceived that they were currently making progress, and hence would be likely to participate in order to give something back to the service. This did seem to be the case with the research, that although objectively most of the patients interviewed were still some distance away from recovery, the majority believed themselves to be making progress, and close to recovery. This meant the gathered data were relatively balanced in their reporting of positive and negative experiences.

Transcribing was an area where I feared my motivation for qualitative methods might wane. As a poor typist, and a confirmed fidget, I knew that it was going to be a considerable undertaking. Aside from the time requirements to transcribe the interviews, it raised other issues for me. I noticed initially that I was judging my skills as an interviewer by the number of interjections from myself in an interview, hence if an interviewee required only minimal prompts to elicit pages of uninterrupted prose, I considered that I had conducted a ‘good’ interview, but if they required considerably more prompting, to elicit much shorter responses, then I tended to judge this as a ‘bad’ interview, in that I, as interviewer had performed poorly, and not established sufficient rapport with the interviewee.

Through transcribing more interviews, reflecting on my involvement in them, and utilisation of peer supervision, I actually began to realise and accept that these differences were attributable to personal style and had little to do with my interviewing skills. This forced me to reflect on my own sense of self importance that made me assume in the first place that interviewees’ responses were entirely attributable to me, rather than them being individuals.

4.3 DATA ANALYSIS

I was aware of considerable avoidance on my part before I finally approached the task of data analysis, in spite of knowing it would take a long time, and that by avoiding I was reducing the time available, and increasing my own stress levels (understanding your own psychological traps does not mean you will necessarily address them). Initial coding of the data revealed the vast amount of information I had gathered, more than could ever be covered in one paper, and I began to understand why qualitative researchers end up writing books on their studies, as my 6000 words suddenly started to feel unworkably restrictive. Perseverance and repeated coding helped me shape the data into a more manageable form, but I was surprised by the length of time this took, and at times was extremely frustrated with the process.

Whilst coding, I noticed that my reflections on ‘good’ and ‘bad’ interviews developed, as I found myself becoming impatient with the flowing answers that I’d initially taken as evidence that I was a skilled interviewer. It became clear during the analysis that these individuals were not necessarily conveying more information in their responses; rather they just had a more verbose style. I also found it increasingly difficult to remain non-judgmental during the coding stage due to the repeated reviewing of the same material, until it felt like I had committed every interview to memory. Whenever I see a quote now, I can hear in my head the voice of the person who said it, which can be useful in recalling which transcript contains a particularly illustrative quote, but creates the possibility that because I am so familiar with the data, I may not provide adequate

explanation for others who do not have that familiarity, and I have tried to hold this in mind in writing up the study.

4.4 WRITING UP

When presenting the results of the study, I had to make a decision about whether to include myself, and a discussion of my perspectives and potential bias, as suggested by Elliott, Fischer & Rennie (1999). This was complicated, because as a researcher I like the anonymity and the protection of the scientific writing style, and as a reader I am not naturally drawn to first person research accounts. In addition, my selected journal does not include researcher information in their qualitative papers, and it feels very strange to include personal information in an empirical paper. However, I also find when reading qualitative research that I want to know who the researcher is, and what they brought to their investigation, as often their conclusions can seem slightly tenuous without this information. Eventually I decided to include a brief explanation of my perspective, but it still strikes me as odd when I see it in the paper.

It was difficult to accept that all the information I had collected could not be included in the final paper. Such a large number of themes were elicited that there were sufficient data for a number of papers. It is also hard to accept the number of words it takes to write a qualitative paper, and I had to make some tough decisions about what should remain in the paper to stay within the word limit. At various points during the analysis I contemplated adopting a more hands-off process to the analysis and presentation and instead letting the data guide me completely in what was produced (Grafanaki, 1996). My decision to stay with my

original focus was based on the questions I was trying to answer, and the knowledge that the eating disorders service that had allowed me to conduct the research, were very keen to use the results to inform their practice, and so my study stayed true to its original aims.

I did wonder whether by editing, and choosing a focus, I had biased the results. Any qualitative research endeavour is inherently biased because of the impact of the researcher at every stage of the research process (Hertz, 1997). This cannot be eliminated but may be used constructively to increase insight and awareness (Finlay, 2002). I have tried throughout the process to be aware of my potential areas of bias, and to limit their impact on the study. This was why I coded inductively rather than deductively, reflected with peers and supervisors on my responses to the interviews, made notes of my thoughts and feelings during the analysis process, conducted inter-rater reliability checks to verify that my coding was reliable and transparent, and deliberated at length whether to stay with the original aims of the research, or follow a different path. Hence I feel I have done a lot to manage the bias I may have brought to the research and have used identified bias as an opportunity for reflection, but I am still unsure as to whether this has been enough to make the study valid, or if there was more that I could have done.

The final thing I observed during this process was the problem I had writing the discussion section of my qualitative paper. In spite of producing what are objectively, a clear set of results and recommendations for future practice, my initial attempts at my discussion barely mentioned this, and instead devoted the

whole section to limitations and problems with the research. While these merit discussion, they certainly should not overshadow the results of the study, and when I realised this, I left the writing of the discussion for a few days to reflect on what I had done. The conclusion I reached was that even at this late stage, I still did not entirely believe in the qualitative research process, and the validity of my results, hence I had, almost unconsciously negated them in writing the discussion. I was very surprised by the effect that thoughts I had not really been conscious of could have on my work, so after rewriting my discussion I took the opportunity to review my other papers.

4.5 CONCLUSION

This has been an interesting process, and I have learned a lot about qualitative approaches, and my own thoughts and feelings through conducting this research. I think I now have more belief in my qualitative paper, and can accept the results are interesting, and may have some clinical utility. After thinking my immersion in the research process had overcome my initial scepticism about the qualitative approach, my discussion writing proved me wrong. I am still sceptical, particularly with regard to intersubjectivity, bias, and validity. On reflection, I am not sure the qualitative approach can do much more to convince me because I think the problem is located within me. My quantitative beliefs are too well developed to permit a whole-hearted acceptance of qualitative research, and I feel this is something I will have to address before conducting any further qualitative research.

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APPENDIX 1.1

PATIENT INFORMATION SHEET

Evaluating Services for Patients with Long Term Anorexia Nervosa

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

1. What is the purpose of the study?

The study has been set up to examine the treatment experiences of patients with anorexia nervosa. The Eating Disorders Service is always looking for ways to improve the service it offers and tailor it more appropriately to the patients it serves. It is hoped that by carrying out this study we will be able to do this.

2. Why have I been asked to take part?

You have been asked to take part because you have had anorexia nervosa for a number of years and have had contact with the Eating Disorders Service. During this time you will have experienced a range of different treatments and interventions and we are particularly interested in your experiences of these.

3. Do I have to take part?

No, you don't. This is a research project and so participation is voluntary. This factsheet will hopefully provide enough information for you to make a decision about whether or not you wish to take part.

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you agree to take part you are still free to withdraw at any time and without giving a reason. A decision not to take part, or to withdraw, will not affect your current or future treatment with the Eating Disorders Service.

4. What will I have to do if I take part?

If you agree to take part, you first need to sign the consent form that accompanies this information sheet, and return it to me at the Eating Disorders Service. When I receive this I will send a signed copy back to you for your own records. I will then contact you to arrange a convenient time when we can meet for an interview. This interview can take place at the Eating Disorders Service, or at your home if you prefer.

APPENDIX 1.1

The interview is likely to last 60 to 90 minutes. It will be audiotaped so that it can be transcribed and analysed later. All tapes will be coded for anonymity and will be stored securely.

After the interview you will be asked to complete a questionnaire which will take up to 15 minutes. That is the end of the research study.

5. Are there any disadvantages to taking part?

It is possible that discussing experiences of past treatment might be upsetting for some people. If this is the case then we will ensure you receive support with this. If you are not currently in contact with the Eating Disorders Service, and the interviewer has serious concerns about your physical or mental health, she may recommend that you seek treatment, and will write to your GP informing them of her concerns. The only other disadvantage is that participating in the study will take up to two hours of your time.

6. What are the advantages of taking part?

The advantages of taking part are you get an opportunity to say what you think about treatment you have received, and that your experiences will be listened to, and used to help design new services.

7. Who will be informed of my taking part?

Your consultant, Dr Winston will be informed that you are taking part in this study. In addition we will write to your GP so that they are aware that you are participating in the study. You may take this information sheet to your GP if you wish to discuss the study with them.

8. What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you.

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of this research will be kept strictly confidential. Any information about you which leaves the Eating Disorders Service will have your name and address removed so that you cannot be recognised from it.

10. What will happen to the results of the research study?

The information will be analysed and the results will be written up for publication. There will be no personally identifiable information in the published reports. It is anticipated that written reports will be completed by May 2003. You will be asked at the interview if you wish to receive a summary of the results, and if you do, this will be sent to you when it is completed. Results will also be fed back to the Eating Disorders Service to inform decisions about provision of new services for patients with anorexia nervosa. There will be no personally identifiable information included on the feedback to the Eating Disorders Service.

11. Who is organising this research?

I am organising this research as part of my training in clinical psychology at the Universities of Coventry and Warwick. Dr Anthony Winston and Dr Wendy Phillips from the Eating Disorders

APPENDIX 1.1

Service, and Dr Caroline Meyer from the University of Warwick have also been involved in setting up this study.

12. Who has reviewed this study?

The study has been reviewed and approved by the Warwickshire Research Ethics Committee, whose purpose it is to ensure that research carried out in Warwickshire is ethical, and gives appropriate consideration to those involved.

Thank you for taking the time to read about, and consider taking part in, this study. If you require any further information, or wish to discuss anything in this leaflet, please contact me on 01926 410281 and I will be happy to answer any questions you might have.

Viki Sullivan
Trainee Clinical Psychologist

APPENDIX 1.2

Cov & Warwick Uni
Warwick EDS Research Study
Patient Identification Number:

CONSENT FORM

Evaluating Services for Patients with Long Term Anorexia Nervosa

Name of Researcher: Viki Sullivan (Universities of Coventry & Warwick)

Please initial the boxes and sign below if you are willing to take part in this study.

1. I confirm that I have read and understood the information sheet dated 01/2003 (version 3) for the above study, and have had the opportunity to ask questions.....
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected
3. I understand that my consultant, Dr Winston and my GP will be informed of my participation in this study
4. I understand that sections of my medical notes may be looked at by the researcher where it is relevant to my taking part in the research. I give permission for this individual to have access to my records
5. I understand that interviews will be audiotaped by the researcher. I am aware that any tapes will be coded for anonymity and confidentiality, and stored securely
6. I agree to take part in this study

<div></div> <div>Name of Patient</div>	<div></div> <div>Date</div>	<div></div> <div>Signature</div>
<div></div> <div>Name of Person taking consent (if different from researcher)</div>	<div></div> <div>Date</div>	<div></div> <div>Signature</div>
<div></div> <div>Researcher</div>	<div></div> <div>Date</div>	<div></div> <div>Signature</div>

PAH

12th March 2002Westgate House
Market Street
Warwick CV34 4DETel: 01926 493491
Fax: 01926 495074**WARWICKSHIRE RESEARCH ETHICS COMMITTEE**

The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

		Documentation Reviewed as itemised in ICH guidelines	
1.	* Approved	Protocol	<input checked="" type="checkbox"/>
		Patient Information Form/ Consent Form	<input checked="" type="checkbox"/>
2.	Approved subject to amendments listed below	Indemnity (signed) CTX	<input checked="" type="checkbox"/>
		Protocol Amendments	<input type="checkbox"/>
3.	Rejected for reasons listed below		
4.	Approved by Chairman's Action		

Ethical Committee Minute Number 593/02 Dated 27th February 2002

Protocol Title and Reference Number

RE 511 Evaluating Services for patients with chronic anorexia nervosa
(Victoria Sullivan)

Signed..........Committee Chairman

Dated...22/5/02.....

This approval is subject to the following standard conditions :

1. the study must begin within one year;
2. the researcher must seek the Committee's approval in advance of any Proposed deviations from the original protocol;
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its Completion.

West Midlands South Strategic Health Authority
(Including Coventry, Warwickshire, Herefordshire & Worcestershire)

WARWICKSHIRE RESEARCH ETHICS COMMITTEE

Lewes House,
George Eliot Hospital,
College Street,
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Victoria Sullivan,

Warwickshire Local Research Ethics Committee
Approval Letter
(LREC-approval of amendments)

Dear Victoria,

**RE 511 Evaluating services for patients with chronic anorexia
nervosa**

I am pleased to advise you that the above amendments have been approved by
Chairman/Vice Chairman action and will be ratified at the meeting of the
Warwickshire Research Ethics Committee dated 29th January 2003 . The Committee
works in accordance with ICH/GCP guidelines.

Please quote our RE reference number and title in all correspondence.

Yours sincerely

.....
Paul Hamilton (Chairman)

.....
Date

APPENDIX 3.1

Clinical Psychology Review

Guide for Authors

SUBMISSION REQUIREMENTS: All manuscripts should be submitted to Alan S. Bellack, Department of Psychiatry, The University of Maryland at Baltimore, 737 W. Lombard St., Suite 551, Baltimore, MD 21201, USA. Submit three (3) high-quality copies of the entire manuscript; the original is not required. Allow ample margins and type double-space throughout. Papers should not exceed 50 pages (including references). One of the paper's authors should enclose a letter to the Editor, requesting review and possible publication; the letter must also state that the manuscript has not been previously published and has not been submitted elsewhere. One author's address (as well as any upcoming address change), telephone and FAX numbers, and E-mail address (if available) should be included; this individual will receive all correspondence from the Editor and Publisher.

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TITLE PAGE: The title page should list (1) the article; (2) the authors' names and affiliations at the time the work was conducted; (3) a concise running title; and (4) an unnumbered footnote giving an address for reprint requests and acknowledgements.

ABSTRACT: An abstract should be submitted that does not exceed 200 words in length. This should be typed on a separate page following the title page.

KEYWORDS: Authors should include up to six keywords with their article. Keywords should be selected from the APA list of index descriptors, unless otherwise agreed with the Editor.

STYLE AND REFERENCES: Manuscripts should be carefully prepared using the *Publication Manual of the American Psychological Association*, 5th ed., 1994, for style. The reference section must be double spaced, and all works cited must be listed. Avoid abbreviations of journal titles and incomplete information.

Reference Style for Journals: Raymond, M.J. (1964). The treatment of addiction by aversion conditioning with apomorphine. *Behaviour Research and Therapy*, 3, 287-290.

For Books: Barlow, D.H., Hayes S.C., & Nelson, R.O. (1984). *The scientist practitioner: Research and accountability in clinical and educational settings*. Elmsford, NY: Pergamon.

TABLES AND FIGURES: Do not send glossy prints, photographs or original artwork until

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acceptance. Copies of all tables and figures should be included with each copy of the manuscript. Upon acceptance of a manuscript for publication, original, camera-ready photographs and artwork must be submitted, unmounted and on glossy paper. Photocopies, blue ink or pencil are not acceptable. Use black india ink and type figure legends on a separate sheet. Write the article title and figure number lightly in pencil on the back of each.

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Authors **must** also supply:

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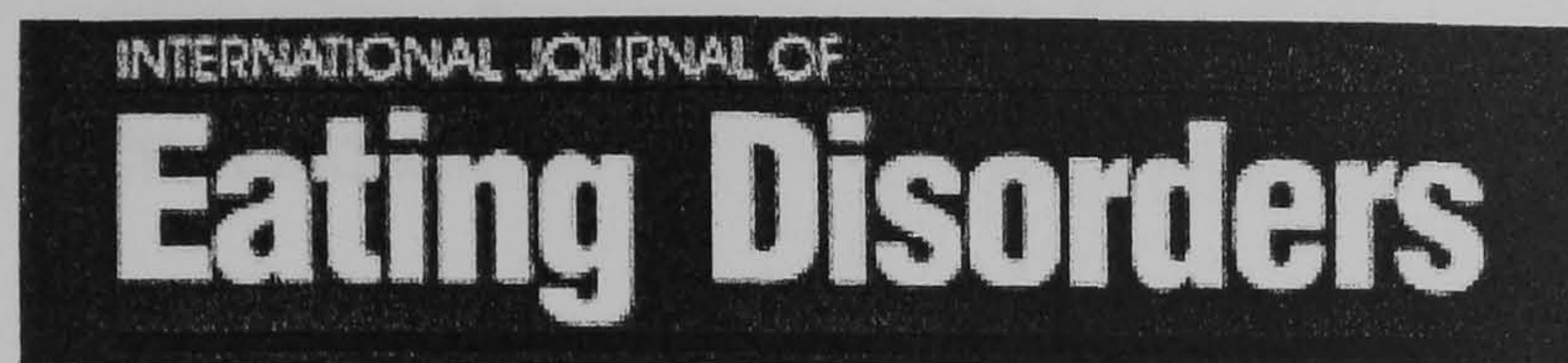
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APPENDIX 3.3

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